Autistics at Work

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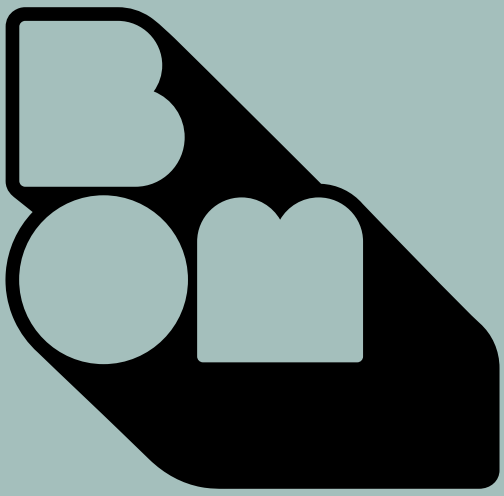

Emotional and practical support for autistic people, and insights for the creative sector.

Autistics at Work takes a psychosocial[1] approach to inequality and the impact of neurotypical norms on autistic people's experiences at work. A concern for emotional wellbeing informs the practical information on offer for those working in the creative sector, and beyond.

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Author: Sonia Boué

A note about the author Sonia Boué (she/they).
Sonia Boué is a multiform artist. She is also a writer on autism and art, and a consultant for neurodiversity in the arts. She specialises in neuro-inclusive practice-led research.
www.soniaboue.co.uk

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Foreword

BOM is an arts organisation that exists to inspire and empower communities through transformational digital experiences. We explore how technology can be used as a tool for change, to make society a better place. Our interests and expertise are in neurodiversity and technology, how technology can help disadvantaged communities, and how it can address environmental challenges.

BOM's programmes have been supporting autistic adults to access and thrive in the digital and creative industries since 2018. During this time, we have worked with WEBworks, an autistic-led initiative that mentors and supports autistic artists and develops autism-led projects. They have supported us on our own learning journey as we've become more neurodivergent aware, providing guidance and a safe environment for autistic people to access digital skills and professional support.

We commissioned Sonia Boué, Director of WEBworks to write this book in response to the overwhelming number of autistic people and companies needing a better understanding of the barriers autistic people face within the workplace and provide pragmatic guidance organisations need to be able to offer sustainable access for autistic members of staff.

BOM runs a wide range of digital skills-based courses, workshops and creative industry career pathway events to support neurodivergent people advance their professional opportunities. We found participants shared the same barriers to entering and sustaining workplace environments time and again. We work with individual participants to try to equip them with solutions but recognise that

more is needed to empower autistic people. In addition, we recognise that organisations need better understanding of these barriers for autistic people and gain strategies to adapt for their access needs.

As an organisation of neurodivergent led people, we have a responsibility to autistic people to bring this experience and process to other organisations within the creative industry. We know from first hand experience that we have hugely benefited from WEBworks pragmatic support for our staff over the years and continue to learn through this process. Autistics at Work aims to provide understanding and empathy for autistic people as well as share insights and strategies for leaders in the arts.

As a late self-identifying neurodivergent black woman, I recognise in my career a lifetime of the challenges referred to in Autistics at Work. The case studies illustrate familiar experiences that I have worked hard to overcome. I have needed to adapt to and compensate for my own neurodivergent needs when working in both the public and private sectors, as well as arts industries. Autistics at Work would have greatly impacted how I changed career, explained my spikey profile to colleagues and helped me understand how to navigate the dynamics of work environments.

Autistics at Work is an essential read for all organisations to implement access and inclusion for autistic people and an essential read for autistic people to be empowered to access sustainable careers in the arts.

Chloe Lawson, Head of Learning and Inclusion, BOM

Introduction

A note from the Author

As autistic people we have two jobs: trying to earn a living and surviving in a neurotypical world. We are socialised to conform to neurotypical expectations. I call this neurotypicalism. In a neurotypically oriented society, we can be misdirected and lack access to basic information about how to live and work as autistic people. I've found that we often miss out on foundational learning and the opportunity to develop confidence and autistic know-how.

Autistics at Work seeks to provide access to such foundational knowledge and thinking. Therefore, the context of our workplaces is not the subject of this book, rather it is the lived experience of being autistic at work.

Mentoring autistic creatives is one of my main roles at BOM and many other contexts, and this is why I include work-life strategies in this publication. For each and every one of my mentees, work is rarely the issue. The issue is most often with people and life, and the overwhelming effects of neurotypical norms and expectations on us.

I am also deeply concerned by how much of our challenge centres on emotional survival. Despite the many cultural advances brought about by the neurodiversity movement, many of us continue to face hostility in the workplace. This is why I have also included strategies for emotional support. Anonymised case studies have been used to make abstract concepts more accessible.

The range of challenges we face can feel insurmountable. In taking a holistic view, I hope to provide autistic readers with information of both practical and lasting impact. For many of us, developing confidence as autistic people can hold the key to our professional development. This is the guiding principle of Autistics at Work.

Sonia Boué

A note about language

Language about autism is complex and evolving. I have chosen to keep the language used in this book as simple as possible.

- Throughout this text, I will refer mainly to autism diagnosis. I mean it to refer to both formal diagnosis and self-diagnosis.
- Late diagnosis refers to any autistic person who is over 18 when diagnosed.
- I have chosen to use the term neurotypical to describe non-autistic people because it is a widely recognised term.
- I will also use the terms neurotype[2] and neurotypes to refer to either autistic or neurotypical people.
- I have adopted the term neurotypicalism because it helps to describe a specific form of systemic ableism.
- TW is used to indicate trigger warning.
- Mentors are referred to frequently and this is because I believe it is so important to have someone to talk things through with. A mentor can be anyone you feel you can trust and who can offer wise counsel, including family members, close friends or colleagues.

Please note that this is not a job seeker's guide. If this is what you need, the National Autistic Society has an online resource for finding employment: https://www.autism.org.uk/what-we-do/professional-development/training-and-conferences/employment/finding-employment

When seeking work you can also look for employers signed up to The Disability Confident employer scheme: https://www.gov.uk/government/collections/disability-confident-campaign

Patterns and trends

As a neurotype, autistic people face high unemployment rates for many reasons relating to social inequality, and because we often think and behave differently to our neurotypical peers. For example, our career paths can often take a scenic route. This can feel haphazard, but it is by meandering that we can acquire the knowledge we need. This can lead to developing a skillset like no other, which can be our USP[3], and an asset in the right context. The creative sector can be a good fit in this respect. However, linear careers are often favoured. Career breaks (to which we are prone) can work against us. Freelancing can be more flexible where short term contracts and specific skills are involved.

We are also known to hyper-focus on a subject well beyond the capacity of our neurotypical peers. On the surface we may seem to struggle to find direction, while honing our niche skills and areas of expertise. This can be viewed as autistic direction - it is how we navigate and process the world. Developing our skills for the job market and applying them is another matter. This is where we may need neurotypical direction and support.

Some of us take jobs below our abilities to accommodate our needs. Routine jobs with low level demands can help pay the rent and support passion projects, or be a stop gap solution rather than a long term option. There can be no one career path, right or wrong way. The most decisive career choices can crumble at the first test - so much can be trial and error. Finding a personal formula for work can feel like solving a Rubix's cube puzzle (unless you're good at Rubix's cube puzzles!) Freelancing can offer a way to shape a career around our skillsets, our interests, and our needs.

Withstanding bureaucracy and calculating the impact of disclosing autism at work can be required to gain access support[4]. While grassroots initiatives and self-led projects serve to generate a knowledge base and vital access resources. Within the freelancing world, neurodivergent creatives have started to use Access Riders as an accessible self-advocacy tool. The creative sector has begun to recognise a need. As hiring processes also present multiple challenges for autistic people[5], self-employment and freelancing can offer an access solution for some. However, freelancing presents challenges of its own. As employees we may benefit from structure and routines, but suffer poor management and a misunderstanding of our social and communication needs.

Mental health check in

As the NAS website concurs[6], autism is not in itself a mental health condition. However, we may have co-occurring mental health conditions, and experience significant stress and trauma, due to bulling, stigma and systemic ableism. As you read through these pages, if your mental health feels fragile, and work is contributing to your distress, you may need to seek mental health support via primary care services or the occupational health department at work.

The Association of Neurodivergent Therapists has a directory of practitioners: https://neurodivergenttherapists.com/directory/

Thriving Autistic (non-profit) hosts the global Neurodivergent Practitioners Directory, of neuro-affirmative practitioners: https://neurodivergentpractitioners.org/

The Samaratans call line is open 27/7: https://samaritanshope.org/our-services/24-7-helpline/

Please do not hesitate to reach out to family and friends for support if you are unable to access services. Waiting lists are currently long, and it can be hard to access specialist services in some areas.

Mentoring insights and support

Foundations

In this section we will explore how neurotypicalism can affect us in the workplace. We will also look at ways to push back. It can be useful to think about some of the challenges of neurotypicalism as a series of tripwires. Knowing where they lie can be the first step towards autistic empowerment.

This section uses two important ideas:

1. Neurotypicalism - a specific form of systemic ableism that works mainly via social norms and practices, which work against the autistic neurotype[7]. They seem invisible to the eye and yet, neurotypical norms are pervasive and can be disabling. We need to know about systemic issues to manage them. The term, systemic ableism, is used to describe ableism that is not intentional, and this is how I will also apply the term neurotypicalism.

2. The double empathy problem[8] - differences between autistic and neurotypical people present a two-way barrier to empathic communication. While we may struggle to empathise with one another across neurotypes, we are able to empathise with our own neurotype. We are different in perfectly reasonable and rational ways. Neurotypicalism can be seen as a misunderstanding of the autistic lived experience. Reeducation is needed at a societal level.

Here, the focus is on providing insights and information at an individual level. As autistic people, we should never be ashamed of what we don't yet know. No-one has told us what we have needed to know in ways we could understand. Conventional wisdoms can misdirect us and we need wisdoms of our own, fashioned from the inside. We may also need support to understand neurotypical norms at work, and so, I place great importance on mentors in all their guises. Please bear in mind that a mentor can be anyone who you trust to offer you wise counsel including family members, close friends and colleagues. While it is possible to receive mentoring through Access to Work and other opportunities in the arts, I recognise that not everyone can access or afford a professional mentor. Trust and familiarity matter greatly, and I have found over the years that my mentors have been wide ranging. Having someone you can turn to, to help you decode the social aspects of work can make all the difference.

These pages are directed at the need for what may sometimes seem like the most basic information. Yet, what may appear common knowledge - such as learning from mistakes - takes on a different meaning when viewed through the prism of neurotypicalism. It is not our role in life to be bewildered, wrong-footed or out of sorts, and we shouldn't have to feel this way. The following mentoring foundations have been written using community wisdom, practice research, and autistic know-how. I hope to inspire readers to develop autistic know-how of their own.

Autistic identity

We all feel differently about being autistic, and that's okay. The elephant in the room is stigma and discrimination, which can result in internalised stigma. I use this term to mean developing powerful (often debilitating) negative feelings about ourselves as autistic people. The following information is relevant for people who are newly diagnosed, and those who feel negative or unhappy about being autistic. The struggles are real, but it helps to know the dynamics at play.

> *"...the navigation of stigma, stereotypes, and discrimination can be exceptionally challenging for autistic people when they conceptualise their identity."*[9]

Internalised stigma is not of our making and can be hard to shake. Life improves when we push back, but it can take time. We can develop a positive autistic identity in whichever way feels right for us. There are no rules for self-acceptance.

Our first stumbling block can be the culture of clinical diagnosis, and a lack of support options for adults. The NHS website contains skeleton resources with links and bullet point advice[10], and states,

> *...you or your child are still the same person as before.*[11]

This is meant kindly, yet it can be profoundly unhelpful. From the inside, a diagnosis can feel like tectonic plates shifting - everything we thought we knew has changed! From a neurotypical perspective, it may not be clear that we could need support to develop a positive autistic identity. I'm certain this will change as autistic research filters through[12]. There is also research about identity that confirms my experience,

> *...identity formation may be challenging for those diagnosed later in life.*[13]

In future times, I think the need for a transitional process will be recognised as, autistic identity transition.

Autistic identity transition

The term, autistic identity transition, has developed through a series of collaborative conversations with Professor Nicola Shaughnessy[14], to describe an individual psychosocial experience. This can require us to make significant adaptations to our mindsets, including how we view (and feel about) ourselves. It can influence the choices we make and bring a sense of agency to our lives. We may need time to sift and discard aspects of our social conditioning - including internalised stigma. To make an analogy, it can be anything from a software update to factory reset.

Internalised stigma is only a fraction of what I encounter in my mentoring practice - we may need many different kinds of help to adapt. It is wise to have support, and a well supported diagnosis presents the opportunity to develop the confidence and know-how required to assert our needs. We can be empowered to seek access support for work. We are entitled!

This work can be done at any time following a diagnosis. It's never too late, though we may need to pass through periods of grieving for what can feel like lost time. Sometimes, the "if only's" can be overwhelming. Having gone through it, I can completely understand.

Case study

TW: reference to panic attacks

K is an autistic woman in her late 30s. She works part-time, in an art shop. Subject to panic attacks and insomnia, K also finds her job boring and stressful. She feels pressured by the social lives of the other parents at her son's school. K often spends weekends in bed, avoiding socials, and recovering from her working week.

K is referred to a counsellor, and begins to link her panic attacks and insomnia to social demands. The counsellor helps K analyse what the demands represent - memories of school bullying and social shaming. It takes time for K to work through her emotions and identify that she has internalised these experiences and absorbed social shame. She meets with other autistics at a local support group, and begins to feel more positively towards her social needs.

Understanding her needs as an aspect of her identity, gives K the confidence to make different choices, and influences her decision to leave the art shop. This job isn't right for K, and she feels empowered to study for an M.A to pursue her dream of working as a freelance artist. Periods of private study and creativity replace the hours spent masking at the art shop, and K's panic attacks subside. She makes a new friend through her support group.

Conclusion

> *...greater dissatisfaction with being autistic related to lower self-esteem, and higher pride in being autistic related to greater self-esteem. Greater dissatisfaction also related to poorer wellbeing* [15]

Diagnosis is a life event. It can revolutionise our lives, upending the very foundations of what we have absorbed from the neurotypical world. Finding supportive others, and information that is positive about being autistic is essential. A transitional process, like K's, can be private or shared. We don't have to wear autistic pride badges, but we can if we want! Like K, we can benefit from autistic oxygen[16], namely the company of other autistic people.

If you're not there yet, and this seems daunting, please remember that, for many of us, this can be a transition that takes time. Your process will be unique, and your responses to it are always valid.

Aucademy is a community education platform that actively supports positive autistic identity transition with it's content: https://aucademy.co.uk

The Adult Autism Assessment Handbook : A Neurodiversity Affirmative Approach, is a new resource which seeks to insert lived experience perspectives within the clinical setting: https://uk.jkp.com/products/the-adult-autism-assessment-handbook?_pos=21&_sid=4521cd6e2&_ss=r

Understanding the social agenda

You're in the room, but the door is still closed. Everyone is talking in code and missing the point! From an autistic perspective, the neurotypical workplace can be utterly baffling. A good example is the private view or exhibition opening. People talk, drink, and make a lot of noise. No-one looks at the art! Such events are actually for social networking, but it's taken me years to figure this out.

One of the most significant barriers to the workplace is the neurotypical social agenda.

As two distinct neurotypes, we tend to approach and process social contact in a fundamentally different way. Autistics tend to have a strong preference for human connection to be 'about something' - a topic of interest, or a shared goal or activity. This is often how we make friends and form collaborative relationships. This can manifest in an intense focus on the subject of our work, which makes us good at what we do but less able to engage with neurotypical work culture.

Neurotypical culture has a stronger focus on more direct and intense forms of social contact, which can be over-demanding for us. Neurotypical social demands can even be aversive (when forced), but it is vital to distinguish this from introversion - we can be

extroverted[17]. Crucially, we can also struggle to process conversations and social interactions in neurotypical contexts, and this represents a core element of our social disadvantage at work. Introversion does not share this core feature, though we have much in common.

Understanding our social difference as presenting an access need, rather than it being our personal social 'problem' brings clarity, and should circumvent interpersonal issues. However, this need can all too often be clouded by stigma and social misinterpretation. I trialed using the term neurotypicalism for some anti-ableism workshops I delivered at the Wellcome Collection in 2022[18]. I found this helped me to think clearly and talk about social needs and access in ways neurotypical people could understand.

While some of us develop skills and strategies to compensate, many common practices at work can be excluding by nature. This is not intentional, but it is inequitable, as workplaces must be navigated through the prism of neurotypical social agendas. As at school, there is a 'hidden social curriculum'. Circle time and the classroom are replaced by team meetings and brain storming, while playground dynamics are replaced by networking, schmoozing, and power play.

In a wider sense, these are cultural differences which need to be addressed at a macro level. When it comes to access measures, it can be vital to understand how the social agenda plays out as a pattern of behaviours that run counter to our neurotype, rather than being a 'social inadequacy ' on our part.

Top tips

- Frame your social needs in terms of access, rather than trying to address neurotypical behaviours and risk getting entangled in interpersonal matters.
- It makes sense to identify niche skills and seek work low on social demands. We often do better with direct communication and clear agendas.

My blog post, The Art World is Social, provides examples of the social agenda and the need for decoding, and it was featured in a supportive article by a-n, The Artist's Information Company:
https://www.a-n.co.uk/blogs/autism-r-us/post/52533799/
https://www.a-n.co.uk/news/disability-arts-neurodiversity-websites-advice-shows-worrying-sign-autistic-artists-not-visible/

Anna Berry also wrote an article providing a further perspective on the social agenda:

How the art world excludes introverts
https://disabilityarts.online/magazine/opinion/art-world-excludes-introverts/

A short blog post about neurotypicalism - Why we need to think about neurotypicalism: https://soniaboue.wordpress.com/2022/04/05/why-we-need-to-think-about-neurotypicalism/

Breaking the trauma loop

TW: references to trauma and bullying.

The first step is validation. Take a moment. Take a deep breath. You're not imagining the daily struggle. We're beginning to understand autistic lived experiences in terms of heightened exposure to ongoing trauma. The National Autistic Society cites the following cause among others,

> *...social difficulties and confusion (for example difficulties interpreting social cues, misunderstandings and conflicts)...*[19]

Social difficulties are our 'normal', but we are not unaffected! Interpersonal traumas, such as bullying and exclusion, combined with a lack of social support, form the experiences that can be reactivated when we come up against systemic issues in our daily lives.

Once we understand the social agenda, we can see how traumatic responses can be activated in the workplace by 'ordinary' events. We can be subject to overwhelming pressures to conform to neurotypical norms. Our inability to do so can lead to painful instances of exclusion.

This dynamic (neurotypicalism) can come to dominate our lives, and we can become extremely sensitised. As a cultural phenomenon, the issue is systemic but it can feel personal and attacking. A great deal of my mentoring work focuses on managing the emotional impact.

We may, at times, not be able to distinguish between interpersonal and systemic issues - sometimes they are entwined. We can be caught in a vicious cycle where activation leads to the need for recovery time, yet our recovery can make us vulnerable to re-exposure, ad infinitum. Neurotypicalism, on a systemic level is not personal, but it can feel personal on a visceral level, activating emotional overwhelm. I use the term, trauma loop, to describe the way neurotypicalism can reactivate a trauma response. The ability to depersonalise instances of neurotypicalism can make a difference.

There are two things we need to know to help break a trauma loop:

1. Neurotypical people can be hard for us to read. When we don't have an intuitive grasp of neurotypical behaviour we can use other means, such as talking things through with people we trust, and also by drawing on our strengths, including logic.

2. When we are emotionally activated and overwhelmed we are susceptible to interpreting events based on previous trauma.

Yes, we can use our natural ability for pattern seeking, analysis and logic to break the loop, and this approach aligns with the practice of Emotional Logic [20]. Using our natural skills to process events can help us move from reaction to action, and consider strategies and options. This is a skill I believe we can practice and learn[21].

Case study

TW: references to feeling excluded at work.

B is an autistic trans woman in her 40s. She is hypersensitive in group situations.

Not being able to follow a conversation in an important meeting at work has made B spiral, and their mental health is affected. B feels excluded and rejected by the people in the room; she experiences acute social anxiety. She is unable to go to work.

Many of B's autistic friends experience something similar and this suggests a pattern. We carry a history of exclusion within us, and this is sometimes overwhelming. Our feelings are about then and now. Our feelings are valid, but our interpretation of the intentions of those in the room can be skewed. The opportunity to identify and analyse the pattern, offers a rational explanation for B's feelings, she is supported through the 'trauma loop' by her friends, and is able to access her workplace.

B's is now engaged in a different activity and is ready to apply logic. She can move into thinking, this is not about me. An invisible membrane of social norms and assumptions create the conditions for ableism. Systemic ableism is not personal.

B can now think about her need to ask for 'reasonable adjustments' for meetings, for example, pre-meetings with their manager to go through the agenda ahead of time, or a support worker who can take notes and help B process the information they need to feel properly present and included.

Conclusion

> *Emotional logic does two very vital things for people on the Autism Spectrum; it provides a common ground for communication ... and takes out the enigma of emotions present.*[22]

Emotional Logic, uses logical analysis to untangle a complex jumble of events and emotions, which can be a beautiful synergy for autistic minds. Systemic ableism and neurotypicalism can be emotionally activating and painful. Logical approaches can be applied with emotional compassion to validate our experiences. We now know that social confusion can be traumatic, and this could be why explanations (that make sense to us as autistic people) can break a trauma loop. We are thought to be too logical and not emotional enough. We are emotional in our own ways, and so what if we are hyper logical! Let's use it. Applying it to our emotional wellbeing can redirect us towards taking positive action.

Support may be needed for this approach, but with practice it can be internalised, thereby offering a powerful self support strategy.

Freeing ourselves from the comparison trap

TW. Comparisons can be toxic and there is a reference to thoughts of self-harm in the case study below.

Many of us have been there, comparisons with neurotypical people can put our mental health at risk, shatter our confidence and affect our capacity for work. Yet, this is something most of us are taught to do through normative socialisation - aka neurotypicalism. Over the years, I have made it my personal policy not to compare myself to neurotypical people. Doing this one thing has transformed my life and my career.

Learning not to compare our abilities and achievements to those of neurotypical people can become a radical and empowering work-life strategy. It can help us develop confidence in ourselves as proud autistic people and allow us to focus on who we are and what we need. We should never be made to feel shame for our neurological differences. Yet, because our challenges are often invisible we can be disbelieved. Confused by our own struggles, we internalise shame.

Lyla Maeve, has written an insightful article, which includes a key difference between neurotypes - our capacity for work. She refers to a community saying that,

> *Neurotypical people usually have around ten usable hours a day while neurodivergent and disabled people have around four.* [23]

This is a complex issue. I think it's important to honour and own our personal capacity for work, to practice self-acceptance and self-care. While true for some people, this figure isn't a general rule either. Accessible, flexible working conditions can also enable us to hyperfocus and produce results, over and above expectation. In writing this book, for example, I've needed to put in some 12 hour days. Working from home and clearing my schedule has made this possible. There are many ways in which we can excel and be productive (whatever this may mean, for each one of us) with the right accommodations. The take-out for our wellbeing, is to think about our differences without judgement.

So, why is it so hard to free ourselves from comparison?

Thought patterns can be hard to break and we've been primed to make comparisons[24], but it's honestly like comparing apples with pears! We are different not lesser. I think it helps to know that we don't

chose to do this to ourselves, and that this is neurotypicalism in action - the comparison is out there and comes to live inside our heads.

> *"It's very common for neurodivergent individuals to negatively compare themselves to neurotypicals. Even when they excel at something or possess a very important character trait, they downplay it because they don't view it as being important. This comes from a lifetime of being compared to what neurotypicals deem appropriate or typical. The pressure of not being able to meet neurotypical standards eventually leads to shame and internal messages like "I'm defective" or "There's something wrong with me."*[25]

Such shaming is actually systematic. Despite cultural advances and equality laws we can be made to feel like second class citizens[26]. Is it any wonder that we internalise shame? The less understanding and support we have in our daily lives, the harder it can be to push back. I revisit the comparison trap time and again with my mentees. It's okay for this to be a work in progress; we can't nail it every time. Yet, little by little, pushing back can help us explore the world of work our way.

We need genuine acceptance. It is harder to build ourselves up if others knock us back. For many autistic people, life improves when

we can begin to build a community of supportive others. At times of extreme stress and isolation this can seem impossible, I know, I've been there. With each step we take to empower ourselves we're building something better - it takes time, but it's so worth it.

Case study

TW: reference to self-harm.

L is an autistic man in his 40s. He is invited to become a member of a university art committee, as he is a professional artist. L feels ill at ease at his first meeting; the atmosphere is formal and unfriendly. L experiences imposter syndrome. During a subsequent meeting, one especially hostile neurotypical professor boasts, very pointedly, that he himself is a highly talented artist.

L feels crushed. His sole purpose is to be an artist, and it takes everything he's got, yet the professor seems to carve out a successful artist career in his free time. As a result of this encounter, L feels worthless and experiences thoughts of self-harm.

Mentoring helps L identify the professor's behaviour as power play, based on a false comparison. The professor is an amateur, not a professional like L. The committee is a club for 'alpha males' to lock horns over dominance.

L is encouraged to explore what purpose the room serves for him. Will it advance his career? Is it worth persisting? Can he risk exposing himself to psychological harm?

L decides he wants no part in this committee, it's toxic. L checks in with his GP to prioritise his mental health. He can now focus on finding a more appropriate professional organisation where his contribution will be valued.

Conclusion

> *"There are certain rooms and energies that don't serve you, and it's not your job to contort yourself to try to be a version of you that isn't authentic."*
> Jeremy Pope.[27]

Sadly, this case study is not an uncommon scenario. Whatever the circumstances, our mental health comes first. Sometimes we need to remove ourselves from harm's way. Highly competitive environments can present a mental health risk if we're not on our guard.

Learning not to compare is a process of gaining confidence and self-worth as an autistic person. If you're finding self-acceptance a struggle, be kind to yourself and double up on self-care for the road. Rome wasn't built in a day. Neurotypicalism is invisible but real and it can be hard to push back.

The right to make mistakes

TW: reference to the classroom and unfair blame.

To err is to be human...[28]

Yet, some of us are made to feel inhuman and experience chronic and disabling anxiety about getting things 'wrong'. This is a further example of the ways neurotypicalism can make us feel we're not good humans, because we're autistic.

In my work as a mentor, I try to nurture confidence and self-acceptance. We're social beings who need as much validation as the next person. When we're continually made to feel wrong in our formative years we can become anxious and risk averse adults. Robbed of social confidence and the opportunity for positive learning, we may come to fear making errors of any kind. Chronic social anxiety can block participation, thereby creating a vicious cycle of negative learning over a lifetime. Sadly, I have often observed the effects in later life - a sense of social confusion and disentitlement.

With the right support, we can push back. The following two things might have happened to us, and it's worth unpacking them to understand how and why we got stuck, in order to push back.

1. Because we don't think like neurotypical people, we are told we are wrong. Our thinking is not wrong, it's just different.

Case study

> An autistic child corrects a teacher who has told the class that, The Snail, is a work by Picasso. The child is told he is being rude, and is punished for shouting out "Matisse painted The Snail!" Despite appearances, it seems the lesson isn't about who painted The Snail. The boy has broken a social rule by the manner in which he has spoken. He is factually correct, but cast in the wrong, and feels intense confusion and shame.

From a neurotypical perspective, we seem to come at things left field and miss the point, but vice versa! What is actually needed is interpretation, as with any other cultural difference. Mentors and support workers can fulfil such a role for autistic people, but ideally interpretation needs to be two-way and take place on the job. The teacher also needed to understand that the boy was not wrong, autistically speaking. Accuracy mattered more to him than manners, in the moment. He felt he was being helpful. A more informed and compassionate approach was needed, as the boy's neurotype was known.

2. We absorb the idea that we can't learn. We can learn and gain all manner of skills when we can access positive learning. We've been stuck in a negative cycle, but we haven't known it.

Yes, it takes encouragement and opportunity to discover what we are truly capable of - and this is something we may genuinely not know. We have a right to feel safe and be confident learners - a right that many neurotypical people can take for granted.

Case study

TW: reference to panic attack

A is a non-binary autistic artist in their 30s.

A is commissioned to make work for a gallery exhibition. To promote the exhibition, the gallery makes a series of inaccurate posts about A's work for their social media campaign. Mortified and anxious about their work, A asks the gallery director for immediate corrections to be made. A experiences further exposure anxiety due to the public nature of the inaccurate labelling of their work.

Action is not immediately taken, and A becomes increasingly anxious as the days go by. A takes action, messages the person responsible for the gallery's social media, and asks for corrections, and they are quickly made.

A receives an email from the gallery director, informing A that they have made a mistake. A has unknowingly broken an unspoken social rule relating to hierarchy. A's actions

have implied the gallery director has not done their job. The email provokes a panic attack.

Mentoring supports A to process that (notwithstanding certain neurotypical social rules) it is unprofessional and disrespectful to publish errors without speedy correction. A's panic attack subsides and A successfully seeks an apology from the gallery director. A's push back offers the director an opportunity to reflect on the interaction from A's point of view. This leads to further freelance work with the gallery for A.

Conclusion

Each of us will develop our own style when it comes to pushing back. Here's mine.

I now think it's my job to get things 'wrong' from a neurotypical perspective. I feel neurotypical people are often wrong too. As an autistic person, I'm good. I no longer internalise feeling wrong.

It's taken time and a secure social safety net of supportive others to help me get to this point. I've been granted an opportunity to catch up on the positive learning I missed in my formative years. I have experienced autistic empowerment, and I now know what I didn't

know before. We need to live our lives with a margin of error and sense of safety. The kind of 'emotional flex' offered by those who genuinely accept us as we are.

Supportive networks are key, and as a practice, learning to push back really does require the right kinds of support for safeguarding reasons. Without it, we can be exposed to further social harms. Working with a mentor or support worker can help us understand complex social situations and provide learning that can be absorbed and become strategic over time. Working safely, and the role of personal support - in untangling this particular dynamic - can't be underplayed.

Access support

Introduction

We're not Rainman, and we don't all need the same thing! Contrary to stereotype, we are unique and multifaceted beings. We're more likely to be gender diverse, and have any number of neurodivergent profiles and co-occurring conditions. There can be a lot going on. We can also be extroverted, sensory seeking adventurers or duvet-loving home bunnies, and anything and everything in-between. What we may need to live our best lives and access the world of work is unquantifiable. Thinking about access needs can therefore feel overwhelming. What follows is a guide to options, and some mentoring insights to help you work your way through the maze. It can be good to start by thinking about access in the round. Let me talk you through it, step by step.

Access options

What do we mean by access?
This is a good question! I find it helpful to think about types of access in the following ways. You might find a different way.
A flow chart can help to sort out the tangles.

Formal access support (usually for a period of time)
Formal access, is support that requires some kind of bureaucratic process and can involve complex administrative procedures.
You may need to disclose personal and medical information, and go through an eligibility check. There can be an in-person assessment process, to agree about what you need. This kind of access support is likely to be ongoing for a period of time (Access to Work) or employment ('reasonable adjustments'). Accommodations, is more commonly used word to describe the kinds of support you might expect when asking for 'reasonable adjustments'.

One-off support to access opportunities

One-off access support is offered by some organisations and funding bodies to pay for someone to help you apply for an opportunity, grant or bursary. Usually the payment goes directly to the person who supports you. You may need to describe, briefly, why you need support and what you need it for. Arts Council England, and a-n, The Artists' Information Company, offer this kind of support. This kind of access generally involves email contact and/or an online form. Some organisations might have an access support budget and even a wellbeing fund to provide for travel costs, noise cancelling headphones etc.

Informal/ DIY

Access Riders are an informal/DIY access support. There is no formal process and you have to do it yourself! Access riders are also informal in the sense that they can be subject to agreement and sometimes lost sight of when there is organisational chaos. How an organisation responds to your Access Rider can be an indication of their suitability to work with you. Access Riders are generally used by freelancers.

Workarounds or hacks (which are covered in the third section of this book) are also part of the access picture, in my view. We can also consider informal networks as a form of access support - and a source of possible support workers should you consider applying for Access to Work.

Compensatory skills refer to the ways in which we use our cognitive strengths to manage areas of challenge. This can result in some very creative and unusual workarounds, but while this can get the job done, relying on compensatory skills can also drain our resources. This invisible labour can be missed out of the access calculation because it is less tangible and often not thought about, but our compensatory skills have an important role to play. We may need to think about the ways in which they make it challenging to figure out what we need. Access supports can free us from having to compensate, saving time and energy. We may need to combine our workarounds with other forms of support.

Tech support / personal support

Tech and/or several forms of personal support can be available through Access to Work. What you need might be extremely simple and straightforward. For example, using the iPhone dictation option for notes, emails and SMS has changed my life - I just needed someone to tell me how to use it! What you need might be complex, quirky, counterintuitive and highly individual. That is fine too. It's simply good to know that not everyone needs or wants formal supports, and there's a lot we can DIY with widely accessible technology.

Top tips

- Don't be intimated, access can be a light touch process. You can feel your way gradually if formal application processes make you anxious.
- Do seek help with formal bureaucratic access applications to make sure you get the support you're entitled to (see below).

The art of access

Access can also be something of an art, in the sense of keeping things balanced. As in all areas of life we can ask, but we may not get what we need. I think we need to be mindful of our mental health too. The art of it, in many ways, is to minimise re-exposing ourselves to harms while making the most of the opportunities that come our way. Organisations and businesses may truly want to work with us, yet be ill-equipped to provide genuine access. There is often a point of learning in which we can rethink what we need.

Top tip

Run background checks on new people, organisations and work opportunities. It pays to do some research - especially when we are recruited to work with our lived experiences. I look at websites and social media accounts to find out more about an organisation or individual when new work opportunities arise. This gives me a picture of the set-up, and also helps give context to the opportunity. This can be a great safeguarding measure and save time and emotional pain further down the line. Token and ill-informed approaches won't serve us, and are best avoided.

Do I need support?

Not all autistic people identify as disabled. Understanding ourselves as autistic people can be the first stage in a longer journey of identifying as disabled. Our challenges can be invisible, and this can contribute to a sense that we are not entitled to support.
We are! Access can also present something of a maze and options can easily become jumbled in our minds.

The first step can be deciding whether to disclose (tell people we are autistic) at work. This is a decision which may change over time, and according to circumstances. Freelancing can offer an opportunity to disclose in some contexts and not others. I have known individuals who are comfortable disclosing dyslexia, dyscalculia, dyspraxia and ADHD, but fear disclosing autism. Autism seems to be particularly stigmatised, for no good reason!

Top tip

If you fear stigma and prejudice you can use the term, neurodivergent, in many contexts.

Disclosure

Telling people you are autistic is an entirely personal choice. However, seeking formal access support will require some level of disclosure. On the whole, deciding to disclose my autism has altered my experiences in the workplace for the better, but a great deal can depend on the context and type of employment. There are many circumstances in my life where I chose not to disclose. We can be perceived very differently once we do disclose; the benefits and risks of disclosure may need to be weighed up, on a case by case basis. In some instances we may feel damned if we do and damned if we don't. It can be important for us to seek support in working through the complexities of this social calculation.

Employment Autism has created a useful webpage called, I am applying for work. Use the following link and then scroll to the bottom of the Employment Autism webpage to access an excellent drop down Q&A resource: Telling an employer that you are autistic: disclosing: https://www.employmentautism.org.uk/Pages/FAQs/Category/applying-for-work

Reasonable adjustments

In the UK, our inclusion in the Equality Act 2010[29] as a protected characteristic, enables us to seek 'reasonable adjustments' from our employers. The GMB Union has produced two excellent PDF guides to Neurodiversity in the Workplace[30] and The Law and Neurodiversity at Work[31]. These guides are beautifully laid out and clear. They also use respectful language and present well-informed views.

If you decide to seek support at work, your employer can ask to see your medical records, with your consent, and organise an occupational health assessment. Some adjustments can be straightforward, such as noise cancelling headphones and regular breaks, others may be more complex and somewhat fraught. It has been said that,

> *"For adjustments to be meaningfully implemented in the long term, they need to work for both sides."*[32]

While this may be true on the ground, from a lived experience perspective the issue runs in a contrary direction. As autistic people in a neurotypical world we spend our lives accommodating neurotypical people, through masking our autism and trying to work in neurotypical ways. A lack of organisational will and / or capacity on the side of the employers can be at fault, when adjustments don't work out. We must also see the bigger picture and dig deeper into the question of cultural differences - 'reasonable adjustments' can be lost in translation - due to the double empathy problem[33]. However, 'reasonable adjustments' (when they align) can transform our working lives. I recommend finding people who can help you to fight your corner in acquiring the provision you need.

Barbara Sandland has written an eloquent blog post about the autistic lived experience and 'reasonable adjustments', Are we speaking the same language?: https://www.employmentautism.org.uk/blog/are-we-speaking-the-same-language

Rebecca Jarvis has also written a useful summary of access challenges regarding reasonable adjustments and short term work, Being a disabled freelance worker in the creative industries: https://bectu.org.uk/news/being-a-disabled-freelance-worker-in-the-creative-industries

The following PDF guide provides a clear and comprehensive list of pragmatic measures that can be sought according to the nature of each specific challenge: Reasonable Adjustments -Neurodiversity AGCAS (The Association of Graduate Career Advisory Services) Disability Task Group: https://www.agcas.org.uk/write/MediaUploads/Resources/Disability TG/Reasonable_Adjustments_-_Neurodiversity.pdf

Access to Work

Employees and freelancers alike can be eligible for an Access to Work allowance[34]. As a freelancer, you will need to meet an earnings threshold to be eligible, and apply for Access to Work on your own behalf. As an employee, your claim will be handled through your employer. Access to Work won't pay for reasonable adjustments because these are changes your employer must legally make to support you to do your job. Having gone through this process, I strongly recommend seeking expert advice. As Trish Wheatley, CEO of Disability Arts Online (DAO), says,

> *"Access to Work, which is run by the Department for Work and Pensions (DWP), has its own language and terminology that must be understood before applying to avoid the risk of ineligibility."*[35]

When it works well, Access to Work can be transformational in enabling us to do our jobs, but it hasn't worked for everyone I know. There are specific issues with the format that can make it hard for our neurotype. As Trish Wheatley suggests, the language and culture of Access to Work can make for an odd fit with the creative sector, and there are significant challenges in managing an allowance. As freelancers, we must recruit, organise and liaise with our support workers. A common problem for autistic freelancers is that we can lack networks, and struggle to find suitable support workers.

It can help to know that anyone who is registered as self-employed (including family members and friends) can fill the role. There are also several types of support we may be eligible for: equipment, temporary job coaching and / or ongoing support. Good support workers can help us to stay organised and understand social situations, however, whenever people are involved, we can encounter difficulties with interpersonal communication.

It will suit some of us to find people to work with us in any number of ways. I know several autistic freelancers who have created effective micro networks to support their administrative and interpersonal needs. I prefer to manage my creative and admin work alone, but I've needed personal support from mentors to figure out the social tangles. Access to Work is an allowance, which provides a budget to spend in ways that suit your needs.

Top tip

Think about how much time and energy working with another person can demand. Communicating with support workers can be a hidden area of demand - a balance needs to be struck. Personal support has to be accessible for you and not about your support worker's needs and preferences. Sometimes help is not helpful. Personal support needs to be well informed and on board with your agenda. I've seen some excellent practice and some that's not so good. Having the right support worker to suit your needs is what will count the most.

NB. If you need support with money management, it is vital that your support worker is someone you can trust with your financial information! I highly recommend using DAO's excellent guide which is available in multiple formats: https://disabilityarts.online/projects/access-to-work-guide/

The artist, Mahlia Amatina, has also written two excellent blog posts outlining the process as she experienced, it with support from DAO. Mahlia offers many useful tips for applicants.

Applying for Access to Work - Part 1:
https://www.employmentautism.org.uk/blog/applying-for-access-to-work-part-1

Applying for Access to Work - Part 2:
https://www.employmentautism.org.uk/Blog/applying-for-access-to-work-part-2

Access Riders

Access Riders provide a non-bureaucratic means of self-advocacy. This practice is associated with the creative industries and is often used within a freelance context. No formal diagnosis is required. The function of an Access Rider is to advocate for the adjustments we need as freelancers that are not covered by Access to Work. While they're not binding documents, Access Riders can form an important part of a working agreement with an organisation and provide a strong entry point for negotiation. For autistic freelancers in particular, Access Riders can take the labour and potential confusion out of conversations about what we need.

The beauty of an Access Rider is that we can be selective in what we share - for example we don't have to give details of our diagnoses or say why we need particular measures. It can be powerful and affirming to frame our challenges on our own terms. Access Riders can be designed in many formats. It can be a voice note or a video, if writing is not your thing.

How to write an Access Rider

The most common thing I hear from autistic people regarding Access Riders is, I don't know where to start.

It helps to structure Access Riders around the contexts and situations we have experienced before. Having concrete examples in mind is a great place to start. It helps to be as concise as possible, while covering the things you feel you need to say. Long documents can be overlooked in a busy schedule. We need our Access Riders to cut through the noise.

Top tips

- Filter the information you include. It is useful to think about what can be changed as well as what could ideally be changed.
- Request a single point of contact when working on a new project. Where larger organisations are concerned, it can be confusing to deal with a team of people.
- If emails are a barrier, ask for WhatsApp or SMS. Perhaps voice files work for you? Put it in your Access Rider!
- Think about where your Access Rider is going to land and who will see it. You can include details about privacy and confidentiality.

Diagnostic reports can provide useful information, but it can be difficult to translate clinical observations for your Access Rider. Template examples can help bridge this gap. I highly recommend Access Docs for Artists which provides accessible templates and information for creating Access Riders.

Access Docs For Artists: Information on writing an access document for disabled artists by Leah Clements, Lizzy Rose & Alice Hattrick:
https://www.accessdocsforartists.com/homepage

The open template provided on the DAO platform is also excellent.

Access Rider Open Template by Alexandrina Hemsley :
https://disabilityarts.online/magazine/opinion/access-rider-open-template/

I have also included my Access Rider as an appendix. Notice that I don't mention autism. This is good example of code switching. Code switching identities can be useful to manage a variety of settings. I have also chosen to make my Access Rider a general document, and stated that more detailed access requirements may be needed for specific projects. This helped simplify the writing task, and provides a document that is quick and easy to read. I have asked for what I know to be practical and possible, as an opener.

Self-employment and freelancing

Self-employment in the creative industries in the UK, including freelancers, is disproportionately high. It is double that found in the UK workforce as a whole[36]. We may ask whether there could be a correlation for autistic workers, and whether freelancing in particular presents an accessible option[37].

Freelancing has held one major advantage for me; I have made a career that's me shaped. As a freelancer, I have been able to follow my interests and work flexibly at my own pace. Freelancing offers a means to circumvent many of the barriers to work, but it can also generate very particular challenges which can be disabling. Freelancing in the creative sector can be highly competitive, precarious and chaotic; we are responsible for our own admin and tax returns, and do not have the protections of sick leave or pensions. The following articles provide a window to some of the pros and cons from the lived experience perspective.

The Struggle of Working with Freelance Clients as an Autistic Person: https://medium.com/artfullyautistic/the-struggle-of-working-with-freelance-clients-as-an-autistic-person-223fc97bcd8c

Tips on being a self-employed autistic: https://www.employmentautism.org.uk/blog/tips-on-being-a-self-employed-autistic

Doin' It My Autistic Way: Why Being Self-Employed Was the Logical Solution for Me: https://autismspectrumnews.org/doin-it-my-autistic-way-why-being-self-employed-was-the-logical-solution-for-me/

Access insights

Spiky profiles

Learning about spiky profiles was a eureka moment for me. Knowing about them - if you have one - can be essential to understanding and articulating access needs.

> *One of the primary things I wish people knew about autism is that autistic people tend to have 'spiky skills profiles:' we are good at some things, bad at other things, and the difference between the two tends to be much greater than it is for most other people.*[38]

Spiky profile is a term used to describe the cognitive profile of individuals with an unusually uneven range of abilities across a predetermined set of measures. Knowing we have a spiky profile can be a mixed bag, but I've found it useful and affirming. We have neither imagined nor invented our struggles. We have a means to describe why we need help with 'ordinary' tasks when we excel in other areas. Some people use the term 'spiky skills' I also like the term, 'niche skills'. Having clear language about this particular challenge can transform the way we approach access.

How do I know if I have a spiky profile?

Blog testimony

Reading what other autistic people have written about their own experiences can be extremely helpful in identifying the contrasts in our abilities, which we may have found hard to identity and explain. You will also find reflection and affirmation.

> *"My life is a study in contrasts. I can hold my own in a meeting with senior managers discussing strategic policy but struggle to make a phone call to change a medical appointment. After a morning structuring my thoughts into a written submission, I head out to buy lunch and put a dint in the car as I back into a railing. I provide advice to colleagues throughout the day but I can't remember if I had a shower yesterday or whether I've paid the electricity bill and who knows what I did with the car keys when I came home."*[39]

Diagnostic testing

You may have undergone cognitive testing which can sometimes form part of a diagnostic process for autism, though this varies. Cognitive testing is also used to identify learning difficulties like dyslexia and dyscalculia. We may need a formal diagnosis to access some of the support we need; and a thorough report can provide a framework for Access Riders and applying for Access to Work. It can be painful to read diagnostic reports - so please take care with this option (and the information below).

Complex spiky profiles

Access to detailed information, such as that found in a psychological assessment, can be extremely useful. Some of us have particularly complex profiles, and areas of strength can be obscured by specific learning difficulties. In my case, strong verbal reasoning abilities had been obscured by my dyslexia. Knowing about this has given me confidence, enabling me to compensate for my dyslexia and take on writing commissions which play to my verbal reasoning abilities.

Spiky profiles are not part of mainstream discourse. Due to a lack of understanding, we can be expected to perform across the board, and are often disbelieved when we can't. Being able to talk about a spiky profile can help explain, in clear terms, why and how flexibility and support are needed.

Executive function

Executive function is often mentioned whereas spiky profiles are less known about. Executive function helps explain a significant area of cognitive function that can form part of a spiky profile and impact on our abilities. It is thought that as many as 80% of autistic individuals have executive functioning challenges.[40]

> *In practice, executive function is a slippery concept. Sometimes it looks like responsibility. Sometimes it looks like self-discipline. Sometimes it looks like being a competent adult. If you have poor executive function, people might mistake you for being disorganised, lazy, incompetent, sloppy, or just plain not very bright. Why? Because executive function encompasses so many essential areas of daily living. Nearly everything we do calls on areas of executive function. Cooking. Cleaning. Parenting. Work. School. Self-care.* [41]

Knowing about executive function as a key area of challenge gives us a framework to tackle the struggles with everyday stuff. Executive function relates to planning and self-organising across almost every aspect of daily life. A difficulty with executive function relates to challenges with working memory[42]. Mundane tasks can be difficult for us to complete, when we can't hold onto short term information. We are also more likely to be distracted. Time keeping and our ability to manage our workflow can be a problem. Many of the suggested hacks in, Section three, address the issue of executive function.

Mentors and gateway buddies

We may not have a large number of contacts and that's okay, one genuinely helpful and supportive person can be enough.

Mentors (in many guises) are my main access supports. As autistic people, we may benefit from help to decode the social agenda and manage interpersonal difficulties at work.

A mentor can take almost any form. It can be a colleague or an access support worker, someone in your family, a neighbour or a friend. A gateway buddy is usually someone who can be with you in challenging environments and situations, to act as a social safety net. The main qualifications for your chosen support is that they can be trusted and understand your needs.

We can be eligible for an Access to Work allowance for personal support, including mentoring and/or a gateway buddy[43], although the generic term used under this provision is, support worker.

Case study

TW: reference to mental breakdown

H is an autistic graduate in her mid 20s. She was unable to access support at university and feels feels mentally broken. She can't imagine how to apply her learning in the world of work. After some recovery time and a course of anti-depressant medication H takes up a short internship.

M is H's supervisor. He notices H's potential and they make a positive connection. M takes H under his wing. With M in her corner, H does well at her internship and develops confidence. M invites H to work socials. M encourages H to think about further study, and helps H find more temporary work.

With M's support, H has begun to imagine her future.

Conclusion

Whether we are autistic or neurotypical, we all need support sometimes. There is no stigma or shame, and a safe person can help us stay in the game.

Toxic people

TW: references to bullying, exploitation and abuse.

Managing people can be an access need. We can be open-hearted and enthusiastic, we can also have a powerful desire for social justice (quite rightly so!). When situations move too quickly for us we can be wrong-footed. I have experienced online trolling and I know how easy it can be to get caught up in harmful exchanges. Sadly, such behaviour can also be encountered in real life.

Wherever a situation involves new people, I think we need to take care. Having people around us we can trust can be essential to help process interactions and events. Safeguarding strategies can also help us to anticipate and avoid potential social harms (see below). We are more likely to experience bullying[44], manipulation and abuse in early life, and this can sometimes continue in the workplace. We may not be aware of what is happening - it can be less obvious when people are manipulative, underhand and/or enjoy conflict for the sake of it. This can make us susceptible to targeting. We also need to be aware of financial exploitation, which can come in the guise of 'helping' - something I've experienced. We can be unusually generous, fair minded, and take people at face value; we might not notice the undercurrents of their behaviour. We may need to give ourselves time to consider people and events more closely - with support.

Suggested strategies

- A regular mentor (person you can trust) to turn to when in doubt, can be a sound ongoing safety net strategy.
- Consider whether people need to know that you're autistic in each new situation. Consult your chosen mentor when in doubt.
- Know that it's okay to step away. You don't have to engage with ableist and / or argumentative people. It is not your job to try to change or educate such people. Genuine people who want to learn more about autism don't tend to argue or create conflict. You may be being trolled.
- If you feel uncomfortable, something could be wrong. Talk it through with your chosen mentor. It can sometimes be extremely difficult to figure out manipulative behaviour on our own.
- Consider keeping a log of any incidents. This can help you process events and share information with others, if needed. Look out for patterns - as a rule, what seems too good to be true probably isn't true.
- Slow things down to allow for time to process interactions. For example, take your time before trusting people who are not part of a known network.
- Back up your financial decisions; you may need someone to help you check things through.

Resource

I like the reassuring tone and information the National Autistic Society offers in this comprehensive guidance on bullying: https://www.autism.org.uk/advice-and-guidance/topics/bullying/bullying/autistic-adults

Networking

Some of us can get through the door. We can excel at masking and we can act the part, but at some point we might well crash and burn. For others, the door is simply shut.

From an autistic perspective, it can be astonishing to learn how much time and energy some people can to apply to neurotypical networking, and that entire books are dedicated to it! One such eye-opening example is NetworkAbility, by Helga Henry and Andy Bass[45].

This is a fascinating book, as it decodes the labour, and the means by which genuine networks can be nurtured and sustained, offering a masterclass in relational networking. Having read it, I now understand. I would need to give up my current work to concentrate on networking![46] Even then, I could never truly nail it or sustain it. The power of small talk is not a power I can wield (or show genuine interest in), though, some aspects of networking could be assisted by a personal support worker. In my own experience, professional networking can spiral, and also misdirect us. It may not take us where we need to go. There can be other ways and means, which take us in more fruitful directions.

For example, I recently formed Gravitation 1-1 collective - a supportive network of three artists who collaborate creatively and share opportunities and contacts. Networking doesn't have to be neurotypical, and you may already be networking in ways that are not obvious to you. I think networking can be about the people who genuinely serve you, and who you will truly benefit from surrounding yourself with. Those people do exist!

I also shared some of my experiences and recommendations regarding networking, in an article for the New York Foundation for the Arts, Business of Art | Neurodivergent Artists Build Community: https://www.nyfa.org/business-of-art-neurodivergent-artists-build-181228133203

Hacks and resources

Introduction

Hacks are, by nature, works in progress. Sometimes we need to shut out the world and pull a duvet over our heads, and that's okay. Self-care is the best hack of all. I can think of nothing better than downtime. As a neurotype, we can sometimes find it hard to link events and adapt to change. When things do change, we might not process why we're not able to function in quite the same way as before.

Understanding the importance to our autistic neurotype of habits and routines, can help when we get stuck. Our daily struggles can be demoralising, but we can avoid self-blame by thinking in terms of executive function (as noted in Section two). Difficulties with executive function - the ability to organise and stay on track - relate to challenges with working memory[47]. This is exactly why we need our habits and routines to get through the day - it is not a negative trait! Routines are literally a form of planning, which take time and repetition to build each time something changes. The beauty of routines is that they can become muscle memory, allowing us to go on autopilot and use our capacities to focus on other things. Go easy on yourself when trying to figure out a new routine, give your muscle memory time to absorb it.

Habits and routines can do the heavy lifting when we need to stay on track and it's why regular work in predictable and structured environments can be enabling for some. The more a job provides routine and structure, the less demand there is for self-organisation. Many of us need a combination of the seemingly paradoxical: flexibility, routines and structure. For freelancers this presents a significant challenge, because we often need to structure our own days. What we gain in flexibility, we lose in terms of scaffolding. Support workers, electronic reminders and many other measures can be used to help.

Top tip

Embrace your routines (and be prepared to adapt and create new ones as circumstances change).

Resources

Life Hacks for Autistic Adults: https://shop.autisticinnovator.com/en-gb/blogs/the-autistic-innovator/life-hacks-for-autistic-adults

Autistic Life Hacks: https://autistrhi.com/2018/09/28/hacks/

Neurodivergent Rebel also has a website page dedicated to life hacks which includes videos: https://neurodivergentrebel.com/category/life-hacks/

Ten top hacks

1. Save Our Spoons (S.O.S)
Keeping going is exhausting, right?

We talk about decompressing, which can be a process involving rest or activity, but we need to be aware of why we feel exhausted. It takes more capacity to compensate for our neurological challenges than the average person, to get through the day. The challenges of fatigue can be supported by a beautifully simple theory.

Spoon theory, for those who don't know, is a way of describing energy when you experience fatigue due to neurological and other conditions. Measuring energy in spoons, helps calculate our daily capacity. Fatigue also affects our ability to function, though we may not, at first, fully understand how our neurology lies at the heart of it. I think that the need to look after our brains should inform our daily habits and routines, because it can make such a difference. Some days can be better than others, and there are many things we can do to conserve spoons. As, Christine Miserando, who coined Spoon Theory has said - we need to live our lives with an extra spoon in reserve[48].

I find Spoon Theory works so well for the guilt I might otherwise feel, of needing to take things slowly. My processing issues are invisible, but spoons are objects I can relate to.

These are my personal best spoon savers:

- I try to calculate the recovery time I need for each big demand.
- I think about the day / week ahead. I make a mental note to pace myself.
- I guard my calendar and space out meetings.
- I let people know I need remote options where possible.
- I select in-person events carefully.
- I think about what kind of rest I need. It could be a walk (brain rest) or a sleep (body rest).
- I cave in when I need to! A nap or a snack can offer an extra spoon.

I can save spoons on travel and pick events because I work from home. If you need to go in to work, think through possible adaptations. You can request flexible options (to minimise contact and travel time) as a 'reasonable adjustment'.

2. Cracking what's for lunch

Your routine has gone to pot and you are tipping into overload - hunger can be a flashpoint for executive function. Figuring out what to eat when this happens can be almost impossible, but if we anticipate the problem we can hack it with some S.O.S. and get through the day. Here's how, for those who love repetition.

- Eat, repeat, eat.
- Know that it is okay to eat the same lunch, until you get bored.
- Enjoy choosing something simple and that you love to eat.
- Check it's easy to buy and prepare.
- Check you can buy the ingredients in advance (to cut back shopping and planning).
- Try new option.

When I need to travel, I take a lunch hack with me or use my favourite chain cafe lunch. I can save spoons, avoid flashpoints and stay on track.

3. Cracking saying no!
A battered post-it note on the wall by my desk reminds me it's okay to say no!

People pleasing is a strategy we can often adopt to avoid neurotypical social pressures. I think this is why saying no can cause acute social anxiety, resulting in a tangle of emails, sprawling text messages and awkward conversations. If this causes sleepless nights and takes hours of your day, you're not alone. Social confusion and worrying about causing offence can be root causes. Filtering information and structuring text is challenging too.

Saying no to things is a normal part of life, but it can feel very loaded. You have a right to say no when something is not right. Learning how to say no effectively has taken me time and practice, but it has patterns, and we can learn them! Being able to say no is a skill we will inevitably need in our working lives. Saying no can be empowering and doesn't have to be negative.

The following tips can help:

- Anticipate and prepare - you can create a bank of phrases for when you need to say no. Your personal support can help you to find words that work.
- Press pause and slow things down - in-person meetings and phone calls speed things up and can be pressuring. Use phrases from your bank to buy you processing time (i.e. Let me think about that / I'll get back to you / let me check the details / I'm not sure right now).
- Switch methods of communication - this gives you control and helps slow things down (request moving to your preferred method, i.e. WhatsApp, email, SMS).
- Less is always more - short sentences work well for saying no and help avoid sending mixed messages.
- Don't explain - explanations invite push back when you need the matter to close. If you feel you need to explain do so briefly. It helps to stick to one thing and avoid complex messages.
- Switch off notifications - you don't need to wait for an answer. This will reduce the temptation to re-engage.

4. Cracking social media

Many of us use social media sites, yet they can also be extremely socially confusing. Many of my mentees are tentative about using social media for their work, when it could be useful to them as a tool for professional connection. I've compiled some tips to help decode online networking.

N.B. It pays to remember that posting online is subject to publishing law.

- Online platforms can be overwhelming, and it can take time to find out what works for you. I suggest only following the people and organisations that truly interest you. Only enabling notifications for key contacts helps to filter the noise.
- Using hashtags can be a useful networking tool. Researching relevant hashtags can be a good use of your time, but beware the algorithms.
- Filtering, muting and blocking options can be essential. It is your right to work in a positive and conducive environment.
- Social media can be time consuming. Posting quality content less often can be time effective.
- Regular sharing (scheduled posts) and responding helps build a network - but you don't have to respond to everything. Lasting connections can take time. 'Oversharing' can be a hazard of spending more time online. This is what the Direct Message (DM) was made for.
- By all means share other people's content if you feel you want to, but this doesn't mean they will share your content in return. Don't share for the likes, share your content for you. Tag contacts into posts if you are sure it will be useful, relevant and interesting to them. Repeatedly tagging contacts is often a no-no.
- People respond to positive messages. It's okay to share negatives, but a consistently negative message can be off-putting.
- Social media has to feel good in order to be right for you - it's not something to be suffered. Don't worry if no one likes a post. It's not personal, it's about numbers and algorithms! A watched kettle never boils, and follower numbers are the same. It's good to network for the joys and benefits of connection, your follower numbers will grow themselves.

Autism Wiki has a page listing Social network sites dedicated to autism: https://autism-advocacy.fandom.com/wiki/Social_networks

5. Soothing 'overthinking'

Do you worry you spend a lot of time 'overthinking' things? Processing work interactions can lead to agonising periods of rumination over a conversation or event, or indeed anything that we're uncertain of. We can sometimes get stuck in thought loops to our own detriment.

I think we do this when we need more processing time and have incomplete information, to borrow a phrase. This can affect our ability to function and the concept of incomplete information offers a way to cut through. In economics and game theory, incomplete information relates to situations where knowledge about other people and players is not available to all participants. I think this is a good metaphor for living and working as an autistic person in a neurotypical world. If we can identify what's missing we can often move on. I now use the term 'incomplete information' as a prompt to myself, to talk things through with someone I know I can trust. Pen and paper methods can work too.

Sonny Hallett has created a brief soothing resource to figure out those "loops of concern".

Loops of Concern:
https://medium.com/@sonyahallett/loops-of-concern-ff792eebad03

6. Cracking comms

Like saying no, all sorts of communication can be difficult for us. As a neurotype, when we communicate, I think we are engaged in

an act of translation. We're working extra time! We can spend a lot of time second guessing, but we can't know how our message will land. We may be focusing our attention needlessly. I think, at heart, that cracking comms is about simplifying language. Clarity is most important, I feel, and comms don't need to be elaborate and time consuming. Sometimes an emoji can go a long way! Neurotypical colleagues often like brevity - as it also saves time for the reader.

Access Riders and email sign-offs can be used to state your preferences. Use what works for you, and explore letting people know when you can't access a communication. Good allies understand access needs and are happy to accommodate.

The following S.O.S. works for me;

- I let my contacts know that I usually respond to SMS or WhatsApp quickly and reliably, while emails can sometimes fall off a cliff.
- I use electronic reminders for important messages and emails that can't be dealt with in the moment. I often have to reset reminders, but this takes away the anxiety of forgetting something important.
- I trick myself by using the 'mark as unread' option for emails, so I can keep tabs of unanswered messages. When I do have time, I can trawl my in box to fish them out. You can also flag or create folders for emails if that works better for you.
- I dictate messages, notes and emails on my daily walk, wherever possible. Sitting at my desk to write emails can be a barrier because it takes a different level of concentration.

7. Cracking meetings

Meetings can require a lot of processing, both in real time and online. We need to work extra hard to stay focused, especially when small talk is in the mix. I like meetings to feel friendly, but I need a clear agenda. Finding ways to anticipate and manage this can save spoons. Being expected to speak at meetings can be extremely challenging - we may experience exposure anxiety and / or situational mutism[49] (aka selective mutism). 'Reasonable adjustments' and Access Riders can include specific bespoke adaptations for the demands for speech. N.B. A record of meetings in any format you can access, is a well recognised accommodation. Recording equipment or a scribe can be provided through Access to Work.

The following tips can help:

- Pace your day to save spoons for important meetings. Rest beforehand, if that helps.
- Clear and direct communication is something you can request as a 'reasonable adjustment' or in your Access Rider.
- It's best not to tackle small talk directly - neurotypical people often need small talk for social bonding and that's okay. Sometimes we do need to sit with it (and try the suggestions below).
- Have something with you that you can do while people chat if you don't feel you can (or want) to join in. I know people who knit in meetings! When I need to be discreet, I use jewellery as a fidget toy. If the meeting is informal I check my phone for messages and emails to take a break. I wouldn't do this in formal circumstances or with new people!
- You don't have to join in with small talk. Sometimes I zone out and notice patterns of behaviour. This is something I quite enjoy.

- Your time is also important - meetings need to serve your needs too. Try to use poor experiences to add to your access needs list.

8. Cracking the brief

Knowing that understanding a brief can be a problem is very the first step. We sometimes think we pick up more inferences than we do. Put another way, we may be picking up very different inferences than the ones intended!

The devil is in the detail of understanding what is expected when we take on a new project. We can think we understand, but may be operating at cross purposes, to a greater or lesser degree. I often find that my mentees experience confusion about what they have been told, and such communication tangles can result in more serious problems for them down the line. Misinterpreting the brief can happen to anyone, but I think we are more prone to it because conversations can be hard to process. I've learned never to assume that I understand what is required for a project through conversations alone, especially when dealing with teams of people. The spoken word can be slippery!

N.B. It is wise only to provide services when you have a written agreement. Asking for written back up for your work can form part of your 'reasonable adjustments' or Access Rider.

The following simple strategies can help:

- Don't rely on conversations to agree a project or brief. Ask for written back up for all new projects at work
- Ask for expectations and action points, on both sides, to be noted.

It truly helps when things are clearly laid out for all parties.

- Be aware that contracts and agreements may not include sufficient detail about the work in hand. Back-up notes are an additional support for you.
- Throughout a project, when in doubt, check the brief again. Make sure you're on track
- A mentor / job aide / support worker can help interpret your brief and support you to keep on track. A family member, friend or colleague can be called on if you don't have Access to Work.

9. Cracking concentration

There can be many levels and types of concentration required for work. Switching between them and approaching tasks head-on can be truly challenging. I sometimes feel I'm like a crab, and I need to move slowly sideways towards my admin.

The following insights may help:

- Forgive yourself for finding it hard to concentrate. You're just not ready yet.
- Think about switching tasks in terms of movement. You may need to go somewhere or do something different to feel ready. I go for a walk, make a collage or have nap. Refresh and reboot, in whatever way suits you.
- Activity and environment also seem to matter. I can 'write' a short email when walking, by using diction on my smartphone, but a longer email requires me to sit down at my desk. They feel entirely different! I can reply with voice notes in minutes, but it can take days to build up to a desktop email. Think about changing your environment, activity, and / or devices, when you feel stuck.

- Some jobs require deep concentration - this can be truly impossible in some circumstances. However, we can use noise-cancelling headphones, dim the lights, and switch off notifications. Do whatever works for you without shame or anxiety.
- You can ask for quiet space and dimmed lighting options as 'reasonable adjustments'.
- Working from home can present more options - you can create your very own 'neuro-tunnel'. I need a duvet and my laptop for some jobs, and the only places I can read books are trains, aeroplanes or in the bath. It is what it is!
- Playing ping pong between tasks can also help, I find. Swapping between tasks gives my brain a break and helps me process. Chipping away, by playing task ping pong, can get the job done or two jobs half done!
- Track what works for you, so that you can see if it works next time.

10. Protecting your identity and lived experience

A concern for welfare and emotional safety has run through this book. This hack, is about pulling all those insights and information together, and having them at the forefront of our minds at work. This can be especially important for those of us who work with our identity / lived experience.

Points to remember:

- Your diagnosis and identity are entirely your business. You might want some people to know, but not others. This is your right.
- You can code switch depending on context - think about where you feel safe and accepted and where you feel less certain and more exposed. Using the term neurodivergent can feel less

exposing, if you're worried about stigma.

- Masking autism is sometimes useful to us when we need to get through situations safely.[50]
- Unmasking is not something you need to do in public either, if you don't want to. I see unmasking as something that can be quite intimate - we can practice and become more confident about unmasking in our own time. This is completely up to you.
- Sadly, we may have negative experiences when we disclose autism. I try to use these as points of learning, and use them to avoid future harms.
- Make plenty of space for 'autistic time' - moments in which you can truly be you. Affirmation from other autistic people and your true allies will also provide a form of emotional protection. The more 'autistic time' you can have, the better.

Sector insights

Overview

Autistics at Work has been written for autistic people, but it also serves to inform our would-be allies in the creative sector, by introducing the lived experience perspective. While this section provides 5 key sector take-outs, the main body of the book provides the all important context. Insights have been drawn from the research undertaken to write this book, and from in-depth neuro-inclusive visual arts practice research, and an extensive mentoring practice with autistic people in the cultural sector.

Autistic people have two jobs: trying to earn a living and surviving in a neurotypical world. This can present serious barriers to our engagement with the world of work. A lack of recognition adds to our labour, and is reflected in figures from the Office for National Statistics (ONS): just under one in five autistic adults were in employment in 2022[51]. The true figure of autistic people in work is unknown, as many autistics in work are off grid[52]. Amidst failures in healthcare and social prejudice, autistic employment emerges as an urgent social justice issue. Clearly, more support and recognition is needed to enable autistic people to seek, find and retain work. Hiring[53] and the failure of 'reasonable adjustments' at work[54] are among the major barriers. It must be owned that a neurotypically orientated society creates hostile conditions for autistic people at structural and interpersonal

levels. This form of systemic ableism is specific and can be termed, neurotypicalism.

I think we must turn the question of autistic access to the workplace on its head. The creative sector needs us, and acknowledging our value to the creative industries as workers (and not merely purveyors of the lived experience), seizes on a powerful imperative. Valuing autistic workers must surely reside at the heart of both a social justice agenda and the cultural offer.

The creative sector presents a particular milieu - one in which originality is prized, and neurodivergent culture is in emergence. We face a perfect storm - new opportunities, a demand for neurodivergent content, and a lack of preparedness to meet our needs. The neurodiversity movement and Arts Council England's, Let's Create, strategy, are two of the significant forces at play. For freelancers in particular, the Arts presents an unregulated terrain. While progress has been made, autistic content and representation has acquired a new value within the Arts ecology as a means to gain funding. As our star rises, so does the risk of token enterprises.

As individuals we must arm ourselves with myriad strategies, in order to work in safety. We need our sector - and those who seek to work with us - to meet us half way, as we carry a unique social disadvantage. It is surely a time of reckoning, in which more honesty is required as we move into a brave new world of neurological inclusivity. The creative sector must catch up with these events to avoid inflicting harms. A focus on autistic culture - and our fundamentally different yet equal lived experience - is required.

Insights and recommendations

A significant neurominority within the cultural sector

The true scale of autistic representation in the creative sector workforce is not currently known. As mentioned, ONS figures for autistic employment do not include the very many autistic people who currently fly under the radar - including those working in the creative sector. Indeed, it has been suggested that the creative sector has an overrepresentation of neurodivergent talent[55]. It is also recognised that true figures of autistic spectrum prevalence are unknown and are likely to be significantly higher than current estimates[56]. Consequently, autistic people represent a more sizeable minority than previously imagined. Advances in knowledge about autism has led to greater levels of recognition in recent times. The publication of, Neurotribes: The Legacy of Autism and How to Think Smarter About People Who Think Differently, by Steve Silberman (2015), transformed the global cultural landscape. We are experiencing a moment of cultural emergence. At grassroots level, it is known that we are many.

> *The number of people diagnosed with autism has jumped by 787 per cent in the past two decades, a new study shows, likely an effect of increasing recognition.*[57]

It is becoming clear that autism can no longer be thought of as anything like a 1% issue. Our representation and contribution within the creative sector is likely to be exceptionally high.

Summary

We stand at an exciting crossroad. The cultural sector can take a lead in social justice, thought innovation and cultural progress regarding autistic employment, but it must be recognised that we're not there yet. The sector is currently playing catch-up, as the neurodiversity movement breaks through. A secure knowledge base is currently lacking, but can be developed through investing in autistic research and leadership on access. Grassroots activists and breakthrough organisations have the requisite knowledge and experience - their expertise should be acknowledged and called on.

Neurotypicalism - a specific form of systemic ableism - is practiced through everyday norms that seem invisible, yet they are pervasive and often disabling. A deeper understanding of the effects of neurotypicalism in the workplace is needed, to take active measures.

Autistic people must not be viewed through the lens of a condition, if we are to gain equal access to the workplace. It is vital to place value on our work and our lives, and recognise that we suffer both economic disadvantage and emotional harms. Understanding where those harms lie can create the conditions for an urgently needed culture shift.

The inherent difficulties in gaining access support represents a further layer of inequality within our population. The access services available can also only go so far, where systemic ableism and prejudice remain. Access measures can work well for some, but they can often fall short of what is actually needed. Currently, the burden of labour in seeking access support lies with the socially disadvantaged individual. Indeed, the very systems and means by which we must seek access support are often disabling. Innovation in working practices and environments could remove many of the barriers at source.

The following 5 insights are drawn from Section one - Mentoring insights and support, in which case studies offer a window to the lived experience, and can assist the non-autistic reader to enter a zone of empathic learning. By combining mentoring and sector insights this resource can add something new to the growing knowledge base.

1. Recruitment

There is an obvious need for attitudinal change, and it is logical that hiring processes be informed by the lived experience.

> *By having solely neurotypicals design the recruitment process and work environments, we exclude neurodivergent people.*[58]

> *The Institute of Leadership and Management (2020) found 50% of managers were willing to admit their discomfort in hiring neurodivergent individuals.*[59]

Hiring processes present multiple barriers for autistic people, due to systemic issues and plain prejudice. This is a key insight for the creative sector, in particular, as it stands to benefit from our inclusion[60]. Clearly, vision, creativity, and investment in autistic leadership are required to enact culture-shifting change.

- On an immediate and pragmatic level, more can be done to improve recruitment by offering flexibility, such as waiving conventional conversational interviews - offering alternative application formats to suit the applicants needs, providing interview questions in advance, allowing notes to be brought into interviews - and allowing for unusual career paths and career breaks in CVs.
- Clearly, attitudinal change is required for access measures to be effective.

2. Safeguarding identity

There is a need for ethical engagement with autistic workers regarding identity.

Neurodiversity is a new concept for the creative sector, but it has a particular role to play in supporting work centring positive autistic identification[61]. A knowledge base for working with autistic people is yet to be established. This presents a risk for autistic workers, and also risks our misrepresentation in cultural products and outputs.

While cultural advances have been made, it must be recognised that autism remains a stigmatised identity in the wider society. Arts Council England have taken a lead and being seen to actively counter stigma would be a welcome move by the cultural sector at large.

- Autistic people need to feel safe and confident in our identity at work - we also have a right to privacy and opportunities should not be dependent on identity disclosure.
- Autistically informed, active measures for ethical safeguarding frameworks are needed, particularly when work involves sharing or representing the lived experience.
- It must be recognised that disclosing our autistic identities can expose us to harms, including tokenism and tick-boxing.
- The lived experience should not be used to achieve key performance indicators, for funding.

3. Education

We have an opportunity to change the landscape through autistically informed education and training, centring the double empathy problem.[62] There is an urgent need to understand autism in a new way. The double empathy problem demonstrates autistic and neurotypical people experience a two-way barrier to empathic communication. While we may struggle to empathise with one another across neurotypes, we are able to empathise with our own neurotype. We are (of course!) equally empathic and sentient beings, capable of all the usual human emotions and responses, in different ways.

The double empathy problem suggests a cultural and collaborative solution to inclusion, as an exchange of equals. What we have previously lacked has been the knowledge to effect mediation. This is now available to us.

- The double empathy problem offers a framework for respectful engagement with the autistic workforce, and restores dignity to autistic workers.
- Autistic inclusion emerges as a two-way communication challenge, requiring translation and mediation, as with any other cultural or language difference.
- Currently the labour of translation lies with the autistic individual and this is a significant barrier to access.
- Autistic communication needs are not limited to add-on access measures (i.e. easy read formats).
- Levelling the playing field requires an understanding of our cultural difference - as equal not 'defective' - and as requiring translation and / or mediation at point of contact.

4. Trauma informed practice

Neurotypicalism has a significant ongoing and detrimental mental health impact on autistic people. This has gone largely unrecognised. The National Autistic Society has recently cited what autistic people have always known - we experience ongoing trauma in neurotypical environments. Among the causes are the "social difficulties and confusion"[63] we often encounter on a daily basis. We face a continual risk that we will be re-traumatised, by ongoing and repeated systemic exclusions. Many work practices can be excluding by nature, due to the dominance of neurotypical norms.

We know that many systemic harms are unintentional, but we need urgent action and wider change. Autistic workers have a right to feel safe at work, just like anyone else.

- Anti-ableism training and a practice should include an understanding of neurotypicalism as a specific form of systemic ableism.
- It must be recognised that the ongoing effects of neurotypicalism on autistic people represent trauma.
- Active measures are required to support autistic workers in the cultural sector who experience trauma[64]. Validation and understanding are vital.

5. Access

Gaining access support can involve unwieldily and laborious processes for autistic workers - this can be a barrier for many. We need genuinely accessible and sustainable access in order to seek, gain and retain employment.

Currently the labour of accessing the workplace can be a job in itself. In many ways access provision represents a 'sticking plaster' approach to supporting autistic and neurodivergent people with adaptations for hostile conditions in the neurotypical workplace. While we do need access support, this system can seem illogical and counterintuitive, from an autistic perspective. It takes a huge amount of effort for an autistic person to push against the neurotypical tide. How much better it would be to adapt conditions and adopt neurodivergent friendly work practices.

- Access support can work extremely well for some autistic people, though barriers remain.
- It seems that many autistic people are not able to access or make use of access support, due to systemic and bureaucratic issues, and the further layers of inequality within our population.
- The current system is not adequate and more is needed to meet our access needs.
- It can be viewed as the work of the cultural sector to support cultural change for autistic people. There is an opportunity to be at the vanguard, in developing autistic-led practices to improve on access by removing barriers at source.

Footnotes

[1] Relating to the interrelation of social factors and individual thought and behaviour.

[2] https://en.wiktionary.org/wiki/neurotype

[3] Unique selling point.

[4] Top 5 autism tips: employment - disclosing your diagnosis https://www.autism.org.uk/advice-and-guidance/professional-practice/disclosing-employment

[5] Access to employment: A comparison of autistic, neurodivergent and neurotypical adults' experiences of hiring processes in the United Kingdom https://journals.sagepub.com/doi/full/10.1177/13623613221145377

[6] https://www.autism.org.uk/advice-and-guidance/topics/mental-health

[7] https://en.wiktionary.org/wiki/neurotype

[8] https://www.autism.org.uk/advice-and-guidance/professional-practice/double-empathy

[9] Frontiers in Psychology | www.frontiersin.org 7 July 2021 | Volume 12 | Article 699335 Corden et al. Identity After Autism Diagnosis https://www.frontiersin.org/articles/10.3389/fpsyg.2021.699335/full

[10] https://www.nhs.uk/conditions/autism/support/ To be fair to the NHS page, links to community forums and major players such as the National Autistic Society, which has recently begun to update content and messaging to reflect more community perspectives.

[11] https://www.nhs.uk/conditions/autism/newly-diagnosed/

[12] Frontiers in Psychology | www.frontiersin.org 7 July 2021 | Volume 12 | Article 699335 Corden et al. Identity After Autism Diagnosis https://www.frontiersin.org/articles/10.3389/fpsyg.2021.699335/full

[13] https://www.frontiersin.org/articles/10.3389/fpsyg.2021.699335/full

[14] Currently there are no citations. I credit Professor Shaughnessy with coining the term 'autistic identity transition'. We have collaborated on the Playing A/Part Project (https://playingapartautisticgirls.org/project/) and the Neurophototherapy Project R&D funded by Arts Council England, for which a follow-on grant has been awarded; a publication is pending.

[15] Frontiers in Psychology | www.frontiersin.org 7 July 2021 | Volume 12 | Article 699335 Corden et al. Identity After Autism Diagnosis https://www.frontiersin.org/articles/10.3389/fpsyg.2021.699335/full

[16] Autistic oxygen, is a community phrase first introduced to me by friend, fellow advocate and blogger, Alex Forshaw. https://myautisticdance.blog/about/

[17] Autistic and Outgoing: I Thought All Autistics Were Introverts https://www.rdiconnect.com/autistic-and-outgoing-i-thought-all-autistics-were-introverts/

[18] Why we need to think about neurotypicalism https://soniaboue.wordpress.com/2022/04/05/why-we-need-to-think-about-neurotypicalism/

[19] Post-traumatic stress disorder in autistic people https://www.autism.org.uk/advice-and-guidance/professional-practice/ptsd-autism

[20] https://www.emotionallogiccentre.org.uk/what-is-it/about-emotional-logic/

[21] This is not to say that systemic ableism should remain unchallenged or that protecting ourselves removes the injustice.

[22] Using Emotional Logic with people on the Autistic Spectrum https://www.emotionallogiccentre.org.uk/using-emotional-logic-with-people-on-the-autistic-spectrum/

[23] Job hunting in the creative industry while autistic: "We have to pretty much hide our traits" https://www.itsnicethat.com/articles/lyla-johnston-job-hunting-in-the-creative-industry-while-autistic-opinion-creative-industry-151121

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[25] Autism and the Trouble with Comparison https://opendoorstherapy.com/autism-and-the-trouble-with-comparison/

[26] Autistic people are second class citizens https://www.corkindependent.com/2020/02/05/autistic-people-are-second-class-citizens/

[27] https://www.theguardian.com/film/2023/feb/17/jeremy-pope-an-oscar-changes-where-the-comma-goes-in-your-cheque

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[29] https://www.legislation.gov.uk/ukpga/2010/15/contents

[30] https://www.gmb.org.uk/sites/default/files/neurodiversity_workplace_toolkit.pdf

[31] https://www.gmb.org.uk/sites/default/files/neurodiversity-law-guide.pdf

[32] Dr Brett Heasman, DARE (Discover Autism Research & Employment) https://www.autistica.org.uk/news/autistica-releases-report-on-workplace-adjustments-for-autistic-staff

[33] https://www.autism.org.uk/advice-and-guidance/professional-practice/double-empathy

[34] https://www.gov.uk/access-to-work

[35] Barrier-Free Work https://www.artscouncil.org.uk/blog/barrier-free-work

[36] One of the defining features of the creative industries is a high reliance on freelancers whether that is in film, design, tech or the arts. 32% of the creative industries workforce as a whole is self-employed (including freelancers), compared with 16% of the UK workforce (Oct 2019 - Sept 2020, DCMS, 2021).

[37] Access to employment: A comparison of autistic, neurodivergent and neurotypical adults' experiences of hiring processes in the United Kingdom https://journals.sagepub.com/doi/full/10.1177/13623613221145377

A small unrepresentative study focusing on barriers within the hiring process, found that 8.9% of the autistic people surveyed were self-employed, compared to 1.6% of neurodivergent (non-autistic) people and 1.1% of neurotypical people.

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[39] Autism And The Spiky Profile: When you excel at some things and struggle with others https://medium.com/autistic-discovery/autism-and-the-spiky-profile-bc03164e07f

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[42] Working memory is a cognitive system with a limited capacity that can hold information temporarily https://en.wikipedia.org/wiki/Working_memory#cite_note-1

[43] See, Access to Work.

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[45] Networkability https://helgahenry.com/home/networkability/

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Appendix

Sonia Boué Access Rider

This is a general document. Please note that good practice means making time to understand and prioritise access needs. We may need to draft a specific access agreement for our work together. Please let me know if you have any questions.

Overview

- I have neurological and physical conditions which require me to work mainly from home.
- My accommodation needs centre on clear communication and a preference for remote work.
- I require a range of communication options and the flexibility to work at my own pace.
- A focus on detail (who, when, what, why) greatly supports my neurological orientation.

Accommodations

- I need a clear communication strategy to work with you. We will need to allow sufficient time for processing.
- Assigning one key contact will support my access needs. I find dealing with multiple contacts disabling.
- Clear definition and coordination of roles (who will do what/ when) will assist my workflow/ help me regulate anxiety.
- Concise information is the best fit for my neurology. Spreadsheets and dense text are disabling. Voice notes, WhatsApp messaging and brief bullet point lists can be enabling.

- I need a clear and timely schedule for our work together. This will support me to process effectively, factor in change and minimise anxiety. A 'last minute' approach to work is disabling.
- If you are unable to respond to emails etc. a holding message is appreciated and enabling. A lack of response can generate anxiety.
- For IRL participation I may need support to organise transport/ accommodation. I will need extra time to allow for travel and recovery.
- I need sensory information ahead of visiting a venue IRL and a list of places nearby where I can decompress.

About BOM

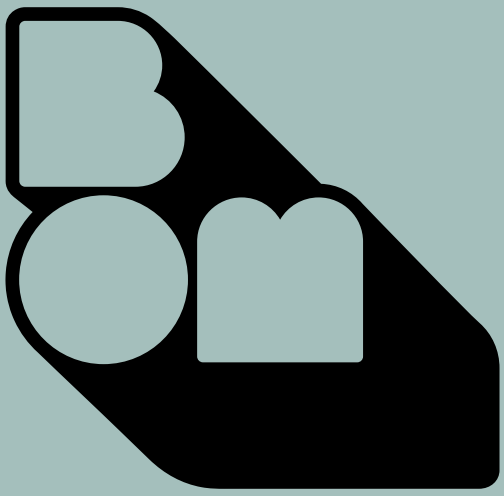
BOM (Birmingham Open Media)
Established in 2014, we are an award winning immersive technology hub working with under-served communities to creatively tackle digital exclusion and produce innovation with immersive technology. Our superb reputation has been built by developing and delivering community-centred projects.

We have producing award-winning projects co-created with the autistic community that have toured nationally and internationally, including the Beholder VR experience exploring autistic perspectives of beauty, and Mood Pinball, a virtual pinball machine gamifying open data for people who are socially excluded.

We are a neurodivergent-led organisation, with a team who have overcome economic disadvantage, racial discrimination, communication differences, and other barriers. This lived experience drives our mission: we are committed to creating opportunities for others to come through and to thrive creatively.

Our expertise and experience is working with people from neurodivergent/disabled. We use immersive technologies to create enriching experiences and useful interventions for people's everyday lives. We share our skills to give autistic children, young people and adults the skills they need to innovate creatively and play an active role in society.

www.bom.org.uk



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